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Palliative Care:

Improving the Quality of Life of All Wisconsin Cancer Patients

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Introduction

More than 285,000 individuals with a cancer diagnosis live in Wisconsin¹. Thanks to increased awareness of cancer's preventable causes and advances in early detection and treatment, the overall cancer mortality rate has declined in Wisconsin for both men and women in recent years¹. Despite these advancements, the physical and emotional effects of cancer continue to create serious challenges for patients and families.

Palliative care addresses these challenges and improves quality of life for patients and caregivers. Palliative care can help Wisconsin's cancer survivors live better, in addition to living longer, and is increasingly promoted as an essential component of quality cancer care².

What is Palliative Care?

Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illnesses³. It focuses on providing patients with relief from the symptoms, pain, and stress of serious illness—whatever the diagnosis. Palliative care teams are interdisciplinary and may include doctors, nurses, social workers, chaplains, and other specialists, depending on a patient's case. ➡

KEY POINTS

Palliative care is:

- specialized medical care that **provides relief** from the symptoms, pain, and stress of serious illness, improving the quality of life of patients and families.
- appropriate at **any age** and **any stage** of diagnosis, and can be provided concurrent to curative treatment.
- a key component of **quality cancer care**.

What you need to know:

In Wisconsin access to palliative care is uneven. **Across the country**, public and provider awareness of palliative care is low.

Policy opportunities, such as those that support public and professional education, research, and workforce development in palliative care, can expand access to palliative care services and improve the lives of Wisconsin cancer patients.



Palliative care services are tailored to the unique needs of the individual patient and their family. For people living with cancer, palliative care services might include techniques to relieve pain or nausea, support to address anxiety and stress, assistance coordinating care across health care settings, or help facilitating conversations with other physicians to ensure patients understand their treatment plan and how it aligns with their goals of care⁴. Palliative care teams can also address the needs of family members as they seek to balance everyday responsibilities at home or work with the desire to support their loved one.

Palliative care can be provided concurrent to curative treatment and is appropriate for patients at any age and any stage of diagnosis. Hospitals and cancer centers often employ palliative care specialists on staff, but individuals may also receive palliative care services at home or in the community. When a diagnosis is terminal and a patient is nearing the end of life, they may also receive palliative care services through hospice (see Box 1).

BOX 1

Is Palliative Care Hospice?

Palliative care is not the same as hospice, although hospice is one provider of palliative care.

Generally, palliative care is appropriate for all patients with serious illness, regardless of prognosis. Hospice is provided for patients with a life expectancy of six months or less, and (under Medicare rules) requires that patients give up further curative treatment.

A patient's palliative care team can assist with the transition to hospice.

their disease and therefore be unable to fully participate in shared decision-making about their treatment options and goals of care.

Interdisciplinary palliative care teams work with patients and families to help ameliorate these issues, with proven success. In addition to increasing a patient's quality of life and decreasing depression, palliative care has been shown to improve patient and caregiver satisfaction with care, and to improve conversations between patients, caregivers, and providers regarding the goals of care^{9,10}. Palliative care may even improve treatment outcomes. A report released by the Institute of Medicine (now called the National Academy of Medicine) indicated that when a cancer patient's psychosocial needs are met, they not only experience less suffering, but are also more likely to adhere to their treatment regimens and experience more treatment success¹¹.

Another study published in the *New England Journal of Medicine* found that receiving palliative care early in a diagnosis increased survival among some patients with metastatic non-small-cell lung cancer¹².

Why is Palliative Care Important?

There is a substantial need for palliative care services among cancer patients and their families. In Wisconsin, one in five cancer survivors with current pain from cancer or cancer treatment report that their pain is uncontrolled⁵. Nationally, more than half of cancer survivors express wanting more help managing the short and long-term side effects of treatment, as well as support to address the emotional effects of their cancer⁶. Likewise, research shows caregivers can experience levels of emotional distress that can be equal to and sometimes even greater than the patients themselves⁷.

Additionally, fewer than half of patients surveyed by the Cancer Support Community say they fully understood their treatment options⁶. Research from the University of Wisconsin School of Medicine and Public Health found that, in conversations following a cancer diagnosis, oncologists and patients both tend to focus on treatment rather than on the disease itself and on how long, and how well, a patient might live⁸. Consequently, patients may misunderstand

Palliative Care in Wisconsin

Access to palliative care in Wisconsin has expanded in recent years. Before the early 1990s, palliative care in the state was offered only within licensed hospices. However, as the model of palliative care delivery has shifted (see Figure 1), the percentage of hospitals in Wisconsin that have palliative care programs has grown considerably, increasing from



BOX 2

State and Federal Policy Efforts at a Glance

During the 2017-2018 WI State Legislative Session, Rep. Patrick Snyder (R-Schofield) introduced a bill, AB 633, to create a palliative care advisory council in Wisconsin. This advisory council would support public and provider education on palliative care, identify barriers to access, and advise state officials on palliative care issues. The bill was supported by the American Cancer Society Cancer Action Network (ACS CAN), AARP, and the Alzheimer's Association¹⁶.

At the federal level, the Palliative Care and Hospice Education and Training Act would advance workforce development, palliative care research, and public awareness efforts across the country^{17,18}. This bill has been introduced several times, most recently in 2017-2018 by Sens. Tammy Baldwin (D-WI) and Shelley Moore Capito (R-WV) as S. 693/H.R. 1676. ACS CAN joined the Alzheimer's Association and many other organizations in supporting this legislation.

63.8 percent in 2008 to 87.7 percent in 2015¹³. Despite this increase, access is uneven throughout the state and smaller hospitals are less likely to have palliative care programs – only 63 percent of hospitals with fewer than 50 beds have a palliative care program¹³.

This limitation is significant, because as awareness and understanding of palliative care expands, demand for palliative care services is likely to increase. A public opinion poll found that only 22 percent of the public is currently aware of the concept of palliative care, but once educated, 92 percent of those surveyed indicated they would consider receiving palliative care if a loved one became ill¹⁴. The supply of palliative care specialists is unlikely to ever fully meet the demand for palliative care services throughout the state. Therefore, in addition to palliative care workforce development, it is critical that all clinicians be trained in basic palliative care skills – such as pain management, facilitating difficult conversations, and assessing goals of care.

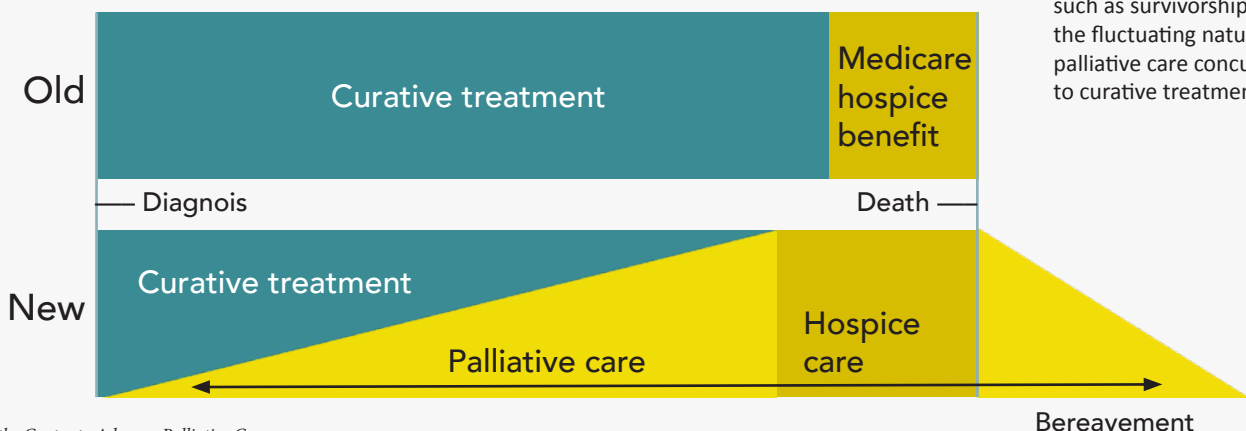
Policy and Program Implications

Policy opportunities at the state and federal levels seek to address current barriers to access in palliative care.

Increasing numbers of states are creating expert advisory councils on palliative care with the goal of improving access to palliative care services in their state (see Figure 2)¹⁵. Efforts to create a palliative care advisory council in Wisconsin have gained some traction in recent years¹⁶. In a recent proposal (see Box 2), members of the council would be appointed by the Secretary of the Department of Health Services (DHS) and tasked with advising DHS on palliative care issues and projects. Projects would include the establishment of a statewide palliative care consumer and professional information and education program, and the creation of a system to identify patients who could benefit from palliative care services and connect them with the appropriate care.

FIGURE 1

Models of Palliative Care

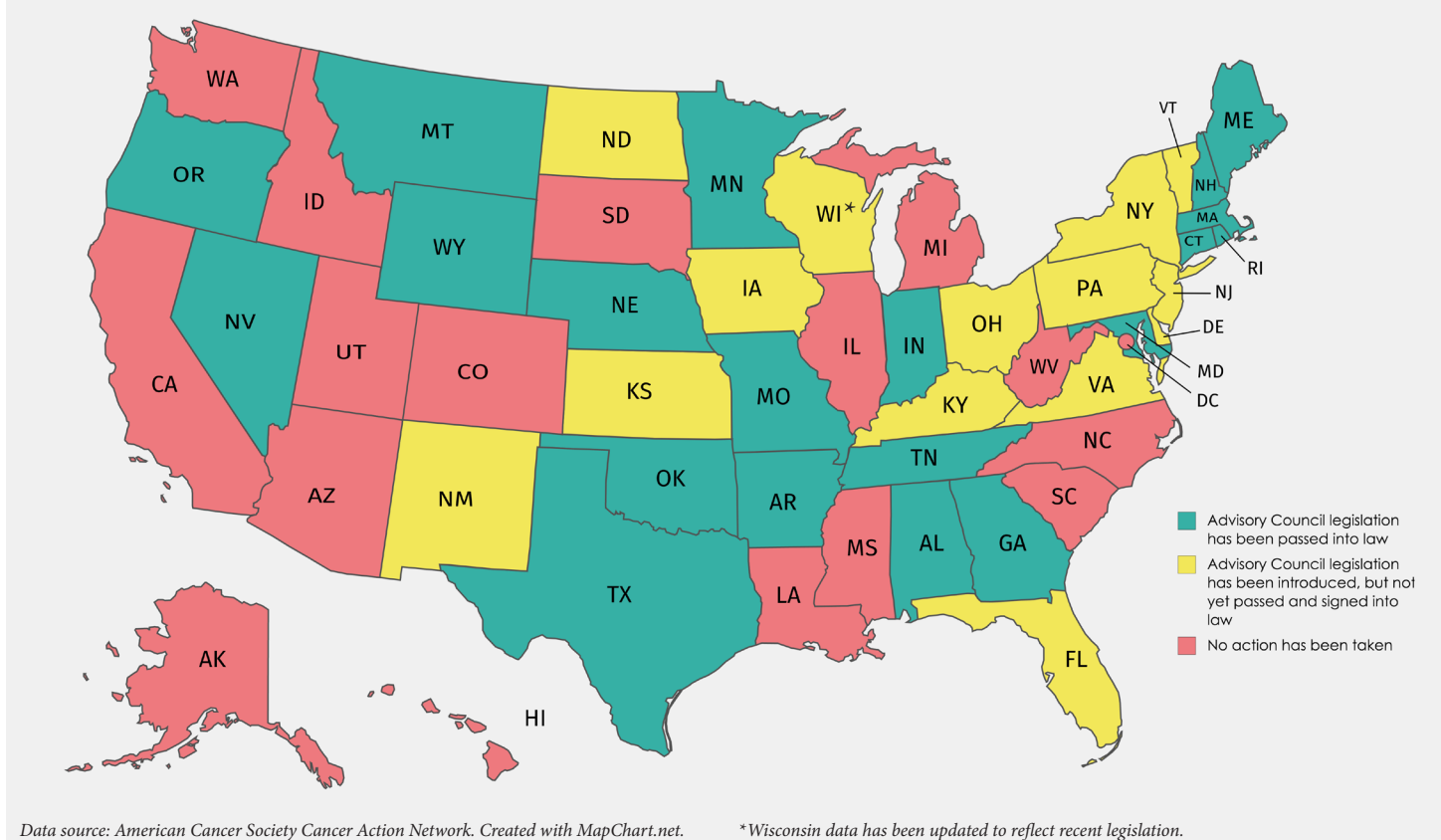


Note: Other models exist that incorporate issues such as survivorship and the fluctuating nature of palliative care concurrent to curative treatment.

Adapted from the Center to Advance Palliative Care

FIGURE 2

States with Palliative Care Advisory Councils



Policies at the federal level would support and expand these statewide efforts, such as the previously proposed and bipartisan Palliative Care and Hospice Education and Training Act, known as PCHETA (see Box 2)^{17,18}. The goals of PCHETA include creating education centers to support and expand the development of the palliative care workforce, enhancing palliative care research, and launching a national education and awareness campaign aimed at health professionals and the public.

From an administrative policy perspective, palliative care aligns with the current shift in health care from fee-for-service to value-based care, and fits well into many of the latest value-based payment models, including the Medicare Merit-Based Incentive Payment System and Oncology Care Model¹⁹. For physicians and practices working to transition to these models, palliative care is a natural choice, given the ability of palliative care services to improve patient and caregiver experiences while reducing unnecessary costs through effective management of symptoms and facilitated communication²⁰.

Conclusion

Expanding palliative care for cancer patients is specifically identified by the WI Comprehensive Cancer Control Plan 2015-2020 as a strategy to increase access to quality cancer care and services²¹.

The Commission on Cancer's Program Standards establishes palliative care as an "essential component" of care and recommends that services be "continuously available" to patients and families either on-site or by referral throughout treatment, survivorship, and bereavement²². We can achieve this by increasing public and provider understanding of palliative care and eliminating barriers to its availability.

Policy and programmatic efforts that increase access to palliative care services have the potential to improve quality of life and advance quality cancer care for people across Wisconsin.

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